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## Parents Gain Custody Of Down's Infant

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ORANGE, Calif., Nov. 30—John and Susan West regained custody of their pain-ridden son Brian today, two years after they refused to authorize surgery necessary to save his life.

Orange County juvenile court commissioner Frank Fasel returned custody to the Wests, one of the few American couples ever to argue publicly for the right of their retarded, deformed baby to die.

The court had taken custody in 1980 so that Brian, who has Down's syndrome and was born without an esophagus, could be fed. Since it became public earlier this year, the Wests' case has become part of a national debate over how far doctors should go to save suffering patients.

Orange County social worker Jerry L. Jahn had reported to the court that he thought the Wests "have accepted the legal issue of not allowing a minor to expire due to the withholding of medical treatment." But the Wests, although agreeing to support efforts to make it possible for the tiny 2-year-old boy to eat, talk and walk, said they would oppose long-term use of a respirator if Brian lost the ability to breathe, which has happened for short intervals during his beleaguered life.

John West, a 37-year-old Santa Barbara physicist, and Susan West, a 36-year-old homemaker and former teacher, visited Brian in the intensive-care ward of Children's Hospital of Orange County after the court ruling.

Brian weighs only 15 pounds, two less than he did before a recent recurrence of serious illness and far less than even the average weight for other children who suffer the form of mental and physical retardation known as Down's syndrome.

At noon today he was sleeping on his back, dressed only in a diaper, on a specially heated bed. A breathing tube was taped to his mouth and his tongue protruded underneath. An intravenous needle was attached to his neck and a gauze pad covered another opening in his neck needed for fluids to escape his deformed swallowing tract. A feeding tube was stuck into his abdomen and a monitoring device recorded his heartbeat.

In the past two weeks Brian has suffered respiratory shock, a massive blood infection and temporary kidney failure, the Wests said. A surgeon has constructed a new esophagus out of stomach tissue to connect Brian's throat and stomach, but it is still so full of scar tissue that he

cannot swallow food.

"Does that look like a 2-year-old kid?" Susan West asked as she and her husband looked in on Brian.

The Wests, who are Lutherans, had argued when Brian was born Oct. 16, 1980, that he faced such a limited life of recurring pain it would be better if he were allowed to die. "It is my strong feeling that there is a better place for a child like Brian," said John West, who, like his wife, has based much of his thinking on their Christian faith.

"Last week during Thanksgiving I tried to think what Brian had to be thankful for," Susan West said. "I couldn't think of a thing."

A national controversy on treatment of deformed Down's syndrome babies flared earlier this year when the parents of a Bloomington, Ind., baby with handicaps similar to Brian's managed, with the help of attorneys, to allow the child to die.

A loud public outcry greeted the

action of the Bloomington couple, who have remained anonymous, and the Reagan administration warned federally funded hospitals that their grants would be in jeopardy if they allowed similarly deformed babies to die in the future. The criticism of the Bloomington case led the Wests, who had avoided publicity, to come forward and show what could happen to such children if they were kept alive.

In his report, social worker Jahn said the Wests were resentful at first because they felt that the hospital and nursing home staff caring for Brian thought his parents did not love him. But, according to Jahn, the Wests maintained steady contact with the staff, visited Brian often and today know more than the social worker about Brian's case.

"Mr. and Mrs. West are intelligent, well-educated parents who have spent a lot of time researching and understanding Brian's medical problems," Jahn wrote.

The Wests said today that the hospital might intervene again if it disagreed with their wishes during another medical crisis for Brian.

They left Christmas presents for Brian at his nursing home in Garden Grove and said they do not plan to try to move him closer to their Santa Barbara home until they find proper facilities.

The Wests, who have a normal 4-year-old son, said today that Susan is pregnant with another boy, due in April. An amniocentesis test has determined the sex of the fetus and that it seems free of genetic defects. "If it had been Down's syndrome," Susan West said, "I would not have hesitated to have an abortion."